Maintaining family life balance while facing a child's imminent death-A mixed methods study

Eskola, Katri ; Bergstraesser, Eva ; Zimmermann, Karin ; Cignacco, Eva

Abstract: AIM: To understand parents' experiences and needs during a child's end-of-life care at home and to identify systemic factors that influence its provision. BACKGROUND: A child's end-of-life phase is an extremely difficult time for the whole family. Parents have specific needs, especially when they care for a dying child at home. DESIGN: Concurrent embedded mixed methods design. METHODS: This sub-study of the nationwide survey, 'Paediatric End-of-Life Care Needs in Switzerland' (2012-2015) included 47 children who received EOL care at home from 2011-2012. We extracted quantitative data from patients' medical charts and obtained information via parental questionnaire and then compared parents whose child died at home or in hospital by computing generalized estimation equations. We thematically analysed interviews with parents who provided EOL care at home. RESULTS: Parents created an intimate lifeworld and a sense of normality for the child at home. They constantly balanced the family's lifeworld with the requirements and challenges posed by the outside world. This work exhausted parents. Parental 'readiness' and social support drove EOL care for children at home. Parents needed practical help with housekeeping and had negative experiences when dealing with insurance. In only 34.8% of cases was a child's EOL home care supported by paediatric palliative care team. CONCLUSION: Paediatric end-of-life care at home is only feasible if parents make extraordinary efforts. If family-centred end-of-life home care is provided by a hospital-based paediatric palliative home care team, which includes paid housekeeping help and psychological support, parents' needs could be better met.

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Background. A child's end-of-life phase is an extremely difficult time for the whole family. Parents have specific needs, especially when they care for a dying child at home.

Design. Concurrent embedded mixed methods design.

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Results. Parents created an intimate lifeworld and a sense of normality for the child at home. They constantly balanced the family's lifeworld with the requirements and challenges posed by the outside world. This work exhausted parents. Parental "readiness" and social support drove EOL care for children at home. Parents needed practical help with housekeeping, and had negative experiences when dealing with insurance. In only 34.8% of cases was a child's EOL home care supported by paediatric palliative care team.

Conclusion. Paediatric end-of-life care at home is only feasible if parents make extraordinary efforts. If family-centred end-of-life home care is provided by a hospital-based paediatric

palliative home care team, which includes paid housekeeping help and psychological support, parents needs could be better met.

Keywords: pediatrics, terminal care, end-of-life care, home care services, parents, needs, experiences, mixed methods, nurses, nursing

SUMMARY STATEMENT

Why is this research needed?

- Little is known about the parental experience and system factors that may influence a child's end-of-life care at home.
- Developing a successful family-centred transitional paediatric palliative home care model depends on identifying the needs of parents.

What are the key findings?

- Parents who provide EOL care to a dying child at home must make extraordinary efforts.
- Parental readiness, and substantial support from family and friends are essential prerequisites for paediatric end-of-life care at home.
- Delayed reimbursement for disability and health insurance place financial burdens on parents.

How should the findings be used to influence policy/practice/research/education?

- To reduce parental burden, we must develop transitional paediatric palliative care models that link hospital and home care; these will guarantee appropriate paediatric end-of-life care at home, especially in rural areas.
- Applications for reimbursement should be streamlined and payments made more quickly to parents who provide end-of-life care at home.

Introduction

A child's end-of-life (EOL) phase is an extremely vulnerable time, pushing parents to their mental and physical limits. Throughout this time, parents have specific needs, especially when the child's EOL care takes place at home.

Most children in western countries die in the hospital (Pousset *et al.* 2010, Feudtner *et al.* 2011a), although the number of children who receive EOL care at home is growing (Schmidt *et al.* 2013, Kassam *et al.* 2014). In the USA 36.6% of the children died at home (or in a hospice); in Great Britain, 45% of children do (Shah *et al.* 2011, NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America 2014). In Switzerland, approximately 350 children (aged 0-14 years) die annually due to chronic complex conditions (CCCs), but we do not know what percentage of those children die at home (Federal Statistical Office 2015, Zimmermann *et al.* 2016). Home care during EOL is also not distributed equally. Children with cancer are more likely to receive EOL care at home than those with non-malignant diseases; further, infants and small children are less likely to die at home than older children (Feudtner *et al.* 2011a, Feudtner *et al.* 2011b). Despite the common occurrence of child death in hospitals, both children and their parents prefer EOL care at home, because family life can continue as normally as possible and the child is surrounded by family and friends (Vickers & Carlisle 2000, Kassam *et al.* 2014).

A child's end-of-life (EOL) phase is a delicate time, during which families are extremely vulnerable, and parents are pushed to their mental and physical limits. Caring for a dying child at home can exhaust parents, impair their health, and cause financial difficulties (Dussel *et al.* 2011, Bona *et al.* 2013). Unfortunately, we know little about parental experiences and needs during and after the period they provide EOL home care, and we do not know which system factors influence that care (Inglin *et al.* 2011). We must learn more if we are to successfully implement a home-based family-centred, inter-professional paediatric EOL care

model. Since children who receive EOL care at home also often receive hospital care, we also need to create specific models of providing transitional healthcare, which can meet the needs of the family as an entity.

Background

Many factors influence paediatric EOL care at home, and they interact on various system levels. Feudtner *et al.* (2011a) developed a multi-level model to systematically explain the complexity, challenges, and dynamics faced by affected children and their parents: 1) the regional and national system; 2) the healthcare system; 3) the family system; and, 4) the individual system.

The **regional and national system level** addresses legal regulations and policies, and socio-economic, ethnic, and geographic factors as major facilitators or barriers to successful paediatric EOL care provision (Feudtner *et al.* 2007, Junger *et al.* 2010). For example, in the US and in the UK, Black, Hispanic and Asian children were less likely to die at home, as were those in rural areas and poor neighbourhoods (Feudtner *et al.* 2011a, Shah *et al.* 2011, Cawkwell *et al.* 2015). The **healthcare system level** refers to specific models that facilitate high-quality Paediatric Palliative Care (PPC). In the U.S. hospital-based programmes have achieved good results by engaging in interdisciplinary collaboration for family-centred paediatric palliative care at home (Duncan *et al.* 2007, Virdun *et al.* 2015). Advance care planning lowered hospital admissions because parents were better prepared to care for their child at home (Dussel *et al.* 2009). The **family system level** describes the many necessary daily tasks of caring for a child, like administering medicine and tube feeding. Adding these duties can emotionally and physically exhaust parents (Woodgate *et al.* 2015). Studies that compared standard care in hospital and PPC at home showed that home care improved the child's and parents' quality of life and decreased the parental burden of care (Groh *et al.*

2013, Friedrichsdorf *et al.* 2015). At the **individual system level**, paediatric EOL care is complex because the length of the EOL phase in unpredictable, there is a broad range of diagnoses (each with few patients), and the paediatric age group spans birth to adolescence; this variety makes it challenging for healthcare professionals to gain experience, and standardise and provide high-quality care (Junger *et al.* 2010). For example, children with cancer are more likely to die at home (Vickers *et al.* 2007). Age is also a factor: 92% of terminally ill infants under a year old die in hospital, while older children are more likely to die at home (Feudtner *et al.* 2007, Pousset *et al.* 2010). All these levels interact, so successful paediatric EOL home care can only be provided when we consider interventions comprehensively, on all system levels.

The Study

Aims

The aim of this study was to provide a comprehensive understanding of parental experiences and needs during their child's EOL care at home, and to determine which system factors influenced provision of EOL home care in Switzerland.

Design

PELICAN HOME was a sub-study within the PELICAN main study, a national multicentre investigation of Paediatric End-of-LIfe CAre Needs in Switzerland (NCT01983852), described in detail elsewhere (Bergstraesser *et al.* 2015). The PELICAN study defined EOL as the child's last four weeks of life. PELICAN HOME sub-study (Eskola *et al.* 2015) used a concurrent embedded mixed methods design, with a dominant qualitative component (Creswell 2011). Quantitative data was extracted from: 1) a retrospective chart review that extracted data relevant to current EOL care practices (PELICAN I); and, 2) a parental

questionnaire survey about parental experiences and needs during their child's EOL care (PELICAN II) (Zimmermann *et al.* 2016). Both surveys were conducted within the PELICAN main study. Quantitative data were embedded in the qualitative data generated from semi-structured parental interviews. This combination allowed us to understand parents' experiences and needs better, and gave us more information about facilitators and barriers to paediatric EOL care at home.

Sample/Participants

For the PELICAN HOME substudy, we used several samples from the PELICAN main study (Figure 1):

Sample 1: Children/adolescents (aged 0 to 18 years) who died from a cardiac, neurological or oncological condition in 2011-2012.

Sample 2: Parents of the children in Sample 1. To explore differences between EOL care at home and EOL care in hospital, we defined PELICAN HOME Samples 1 and 2 as deceased children who spent ≥ 21 days at home in the last four weeks of life, and their parents. We excluded the PELICAN main study diagnostic group neonates from this sub-study because they presumably spend less than 21 days at home in the last four weeks of life.

Sample 3: We invited a purposefully selected sample (e.g., children of different ages, with different diagnoses; family's socio-demographic characteristics) of German-speaking parents from the PELICAN HOME group for semi-structured interviews. We selected a heterogeneous enough sample to give us a broad perspective on our topic. Sample size was determined by data saturation.

Data collection

Quantitative data

The PELICAN HOME sub-study extracted quantitative data from the PELICAN main study. These data were collected by **medical chart** review, restricted to the last 28 days of a child's life, in 13 children's hospitals and general hospitals with paediatric wards, two long-term care institutions, and ten paediatric community care organisations in Switzerland, and from a parental **questionnaire survey**. Both the chart review and the survey were conducted between November 2013 – June 2014. Qualitative data were collected in parental interviews conducted solely for the PELICAN HOME sub-study.

Sample 1: For this sub-analysis, we used the following patient information: child's gender; age at death (grouped); diagnostic group (cardiology, neurology, or oncology); and, illness duration (grouped).

Sample 2: Quantitative data on parental experiences and needs were obtained through the **Parental PELICAN Questionnaire (PaPEQu)**, which was specifically developed and validated for the PELICAN II main study (Zimmermann *et al.* 2015). The questionnaire was structured according to six quality domains of family-centred EOL care, and comprised approximately 90 items. Items were organised into scales (adjectival or Likert-type), or single items with multiple choice or Yes-No response options. In addition to the socio-demographic information, we used single items related to decision-making, bereavement support, and areas that negatively influenced parents' lives. Results of the survey for the main study are reported elsewhere (Zimmermann *et al.* 2016).

Qualitative data

Sample 3: We contacted parents from the PELICAN HOME group who consented to participate in an interview. The interviews were conducted in German in the parents' home between January and April 2014, by the first author or by two study co-workers. The interviewers received special training for the interviews and did not know the participants.

The **semi-structured interviews** lasted about 60-90 minutes and were audio recorded. Interviewers used specially developed interview guideline with open-ended questions relating to each of the four levels of the Feudtner *et al.* (2011a) multilevel system model. It focused on experiences parents had in the last four weeks of their child's life during EOL care at home, and their needs during this distressing time. We used ATLAS.ti 7© software was to manage and organise data.

Ethical considerations

To avoid the most intense period of parental grief, we collected data a minimum of one year after the child's death (Maciejewski *et al.* 2007). Most bereaved parents appreciated the opportunity to share their experiences, and participated for altruistic reasons (Dyregrov 2004). The nationwide PELICAN study was approved by the responsible human research ethics committees.

Data analysis

Quantitative analysis

We used descriptive statistics to summarise individual variables, and considered each variable's level of measurement distribution. We used generalised estimating equations (GEE) to compare the home and hospital EOL care experiences of parents, accounting for the clustered data structure caused by the dyadic design with correlated data between partners (mother and father). The predictor variable was group affiliation; the PELICAN HOME group was the reference. We used generalised linear regression to explore the relationship between the distance of the child's domicile from the treating hospital (0-20 kilometres, >20 kilometres) and the hours of EOL care provided by community care. Data were analysed with IBM SPSS Statistics® 22.0. We considered p-values of <0.05 significant.

Qualitative analysis

We took a mutual inductive and deductive approach to thematically analyse parental interviews to "thematic analysis" (Braun & Clarke 2006). After the first author and two other researchers familiarised themselves with the data, they participated in the peer group that developed preliminary codes and themes to describe the important facilitators/barriers faced by parents who provided EOL care at home. Near the end of the interview, parents were asked to raise specific issues they felt were not covered during the interview, but this inductive approach did not reveal any novel aspects. Similar themes recurred after ten interviews, at which point we determined we had reached data saturation. The peer group then used deduction to categorize the codes they had developed inductively. The system model of Feudtner of al. provided us with a helpful data structure for this task. The peer group generated themes and a thematic map. The six steps of the thematic analysis helped us identify and clarify patterns, and allowed us to constantly move back and forth between the steps, as described by (Braun & Clarke 2006).

After separately analysing both quantitative and qualitative data, the first and last author merged the data while comparing the codes in a matrix with questionnaire data (agreement/disagreement between the two data sets). The embedding process gave us a deeper understanding of the dynamics that help or hinder parents who provide EOL care for their child.

Validity and reliability / Rigor

To ensure qualitative data was trustworthy and rigorous, we used the Guba and Lincoln criteria (Lincoln & Guba 1985). To reach credibility, we conducted a pilot interview to test the accuracy of the interview guideline. This allowed us to member check and revise the questions developed by the research team. Recorded interviews were transcribed verbatim and

read by multiple peer group members, which also reinforced credibility. Five peer group meetings, in which codes and themes were built, and researchers discussed the findings, allowed us to closely inspect the interviews and avoid misleading interpretations; this ensured the accuracy of the analytic process and the credibility of its results. An external senior researcher participated in three meetings to help us critically reflect on data interpretation (internal audit). Use of both quantitative and qualitative data supported the confirmability of the results. All selected quotes were translated to English, and the accuracy of the translation was verified by the co-authors. Evidence of initial validity and reliability of the PaPEQu was demonstrated and published elsewhere (Zimmermann *et al.* 2015).

Results

Sample characteristics

Sample 1: Of the PELICAN I main study sample (after neonates were excluded; n=93), 47 (51%) children were allocated to the PELICAN HOME group. Table 1 provides a detailed sample description of the PELICAN main study and PELICAN HOME groups.

Sample 2: Of the PELICAN II main study sample (after parents of neonates were excluded; n=118), 66 parents (60%) were allocated to the PELICAN HOME group. For more details, see Table 2.

Sample 3: We conducted 10 semi-structured interviews (7 mothers, 1 father, 2 couples). The average age of parents was 44.9 years (*SD* = 5.99). All were married; 6 worked in social professions (e.g., teacher, nurse, kindergarten teacher) and were middle- or upper-class.

Qualitative and quantitative results

The process of EOL care in the home care setting was characterized by an overarching theme: *Creating and balancing the family's lifeworld*[1] *while facing a child's imminent death*. We identified two major phases of paediatric EOL home care (Figure 2):

Phase 1: *Creating and balancing an inner circle to stabilize the family's lifeworld while facing a child's imminent death*. This was an enormously demanding process for parents while they provided their child's EOL care at home. While always aware of their imminent loss, parents wanted to offer the family as normal a daily lifeworld as possible, balancing daily activities and requirements with the challenges posed by the outside world. This balancing act required an enormous amount of emotional work. Yet, many parents experienced this phase as being filled with life and positive experiences.

She was not in good state of health when we wanted to visit the circus, and my husband said: "Hey, we can't go now, she'll have seizures. I don't want her to collapse in the circus!" I said: "We'll go, a little bit of normality will do her good. If we don't, *then* we'll have a problem." So we took the transportable oxygen with us, carried her, and spent one hour in the circus. She got better and better, and sat there watching the show, laughing. When we came home she played circus and hung on a trapeze. (Mother, Interview 1)

Phase 2: *Building a new lifeworld after the child's death and re-integrating into the outside world.* For parents, the EOL process did not end with their child's death. Their memories of the following period were marked by feelings of emptiness, loneliness, and exhaustion. Parents reported on emotional survival, re-adaptation, and functioning in the outside world, which seemed a distant and unreal place where they felt like aliens. Parents needed to

[1] Lifeworld is defined here as the world experienced subjectively and created (by oneself) under current circumstances/environment (Kraus 2006)

reconnect with themselves and redefine family roles in a world that seemed to have changed greatly.

All results are presented according to Feudtner *et al.* (2011a) system level model with following key subthemes.

Family system level

Retaining control and taking decisions enabled parents to integrate caring for the child and completing tasks necessary for the child's EOL home care into a household routine, and to plan a family-appropriate daily structure. Parents who had the skills necessary for care felt more secure and coped better with the situation.

He needed to be fed by nasogastric tube every three hours, and he needed medication every three hours. … His anus praeter was leaking all the time, so I needed to change it at least twice a day ...From the moment when his situation worsened, I did it more often. Well, I did the whole anus praeter care of course. (Mother, Interview 5)

An active parental role increased the likelihood parents would take part in making decisions: 66.2% of parents (n=45) in the HOME group reported that they were *"always"* involved in decision-making, while only 33.8% of parents (23) from the PELICAN main study group said the same. Parents in the HOME group also felt less uncomfortable making decisions alone than those whose child's EOL care took place in the hospital (*OR*= - 1.464; 95%*CI*=[.111,.867]; p<0.001).

Functioning despite sustained exhaustion and sustained fatigue after the child's death were the result of round-the-clock EOL care for a child at home, which demanded tremendous strength and endurance from the parents. The burden of EOL care and daily life sapped energy from the family system and made it fragile, so it fell out of balance easily. This constant demand increased parents' fatigue and impaired their health. Parents from the

PELICAN HOME sample more frequently reported a negative impact on personal health than the parents in the main study group (58.8% vs. 41.2% respectively; $p = .587$).

I drove home in the evening, parked in front of the garage… Do you think I was able to get out of the car?! I remained seated three quarters of an hour, just sat there and slept. In fact, I was at home, but couldn't manage to get out of the car. No energy, empty batteries. (Father, Interview 7)

After their child died, most mothers reported that it took a very long time to recover from their fatigue. Combined with deep grief, the extended provision of 24-hour care led to fatigue that persisted for months and sometimes even years.

The shattered remains are still there, you are alone again (...) By the time it was getting better (...) and I was able to function in daily life again. Earlier, I would pick up the vacuum cleaner and need another week till I had the energy to get up and vacuum. (Mother, Interview 8)

Most parents reported that *support from family and friends* was the most essential facilitator during their child's EOL care at home. Friends gave emotional support, helped care for siblings, and cooked for the family, which let parents spend more time with their sick child.

Our friends cooked us dinner, and when [husband] came home we ate together – fast – and then…our friends alternated with cooking, they prepared it and put it into the mailbox. So that we could spent more time with [child]. (Mother, Interview 6)

The most important facilitator of paediatric EOL care at home was *parental readiness*. Ready parents were strong-willed, with clear expectations about the provision of their child's EOL care and willing to learn the *required skills* for it. They dealt with issues proactively and

fought for their child's wish to be cared for at home. Opting for a child's EOL care at home was based on a deep conviction that it was the right thing for the child and the whole family.

[Caring for our daughter at home] was very, very important for us; we asked from the beginning if she could come home. To us, [it was very important to be able] to do normal things like sitting on the couch, going walking, just normal things. We always had the goal of taking her home (Mother, Interview 6)

The family's financial situation influenced EOL care at home. Because some services and devices were not covered by insurance, or reimbursement processes were too slow, families that had the money to cover extra expenses were at a clear advantage. We found that families in the PELICAN HOME group tended to have a higher annual family income (32.8% fell into the 100 000-150 000 Swiss francs [CHF] category; 3.1% fell into the >200 000 CHF category) than those in the PELICAN main group (30.2%, 100 000-150 000; 1.9%, >200 000 CHF).

Furthermore, there were slightly more *well-educated parents* with a university degree in the PELICAN HOME sample (13.8% [n=9]) than in the PELICAN II main study sample (11.3% [n=6]; $p = .079$; Table 2).

Healthcare system level.

Parents complained that the *absence of home-oriented services* and the lack of professional services were a major hindrance to their child's EOL care at home. Parents sensed the goodwill of healthcare professionals, but community care organisations were often unable to provide the EOL care services they most needed, since these were subjected to rigid structures and schedules. In the German-speaking part of Switzerland, there were hospital-based PPC teams in only two major cities. In addition to the emotional and physical strain of caring for their child, the prospect of searching actively for support was too burdensome for

many parents. And while parents felt a need for housekeeping support, insurers only covered services for the child's care. Of the PELICAN HOME families, 54.3% (n=25) made use of community care, a paediatrician was involved in 50.0% (n=23) of the cases, but 34.8% (n=16) only received PPC specialist care. Families who lived farther away from the treating hospital (>20 kilometres) received fewer hours of community care (Mdn = 22.5 vs. 39.5, p=0.346).

After their child died, some parents felt abandoned by professionals, because professional support stopped and there was no further regular contact. This abrupt break and the *absence of bereavement support* was painful for them. Parents at home had slightly fewer (57.6% [n=38]) follow-up talks with professionals after their child's death than parents whose child died in the hospital (66.0% (n=33), p=.362).

Individual level.

The children in the families we interviewed had suffered from various illnesses and each had a unique illness trajectory. The perception of parents was that community care professionals had limited professional expertise on rare diseases, and occasionally had difficulty fulfilling the family's specific needs. In our sample, children aged < 1 year most commonly received EOL care in the hospital (Table 1), and a much greater proportion of those aged 1-3 years received care at home (Table 1).

National/regional system level.

Most parents considered *rigid and bureaucratic processing of policies/finances* as an additional burden. They experienced reimbursement for medical equipment, supplies, etc., as complicated and protracted. Because the child's illness trajectory and the duration of the

child's EOL care were uncertain, parents needed reimbursement applications to be processed quickly. Unlike the parents of children who died in the hospital, the parents in the PELICAN HOME group needed to perform administrative tasks on their own. Eight of ten interviewed parents felt they were only numbers in the system, and were often too tired to fight for their rights.

First, you waited one year until you get some [refund] for all of what you do at home… As long as we cared for him at home and he didn't have to go to hospital, we couldn't claim any benefit. And that is NOT RIGHT (…) And it was not about the money, money didn't play a role here, because we are wealthy enough and are getting along well (…) I didn't want to argue [about the benefits]. We didn't have the energy to argue. (Father, Interview 4)

Parental needs during a child's EOL care and after the child's death.

The most important parental needs were for *practical help with housekeeping* and for *bereavement support*. Most interviewed parents (n=8) felt a strong need for help with the housework, e.g., cooking, cleaning, and grocery shopping. Mothers also noted the same need for support in daily life activities after the child's death, since they needed rest and recovery time. However, this need remained mostly unmet unless families could afford a cleaner or housekeeper. In addition to practical help in everyday life, parents formulated a strong need for bereavement support and ongoing contact with the professionals involved during their child's illness and EOL care.

This daily household crap – getting groceries, cooking, cleaning, paying the bills (…) It would have been so nice, if there had been somebody to take over all these tasks, and we could have spent the time with our child. (Mother, Interview 1)

I think it is very important that the [professional] support continues afterwards, too. That they [professionals] give you the feeling you are not alone (…) Some of us need more time, some are slower to get back on our feet. Not this attitude of: "OK, the child is dead and that's it" (Mother, Interview 9)

Discussion

We provide novel data on parental experiences and needs during their child's EOL at home, in the context of a multi-level systems model that allowed us to identify facilitators and barriers. Two major themes emerged, in which parental experiences and needs during such an existential event could be embedded: *Creating and balancing an inner circle to stabilize the family's lifeworld while facing a child's imminent death*, and *building a new lifeworld after the child's death and re-integrating into the outside world*.

Creating and balancing an inner circle that protected the family's lifeworld was a prominent strategy adopted by parents caring for their dying child at home. This inner circle enabled parents to focus on their child's needs, and to spend their limited time together as a family. It also provided some "normality" in daily life before the child's death. This process of normalisation emphasized the importance of the nuclear family's privacy and parental focus on the child's well-being; both are coping strategies also used by families with children who suffer from CCCs (Knafl *et al.* 2010). Balancing the family's lifeworld with the challenges posed by the outside world placed an immense burden on the parents, which often caused physical and emotional exhaustion (Kars *et al.* 2011). But the most important driver for a child's EOL care at home was parents' explicit **will** and **readiness** to provide needed care, and to learn required skills. Our findings are in line with those of Dussel *et al.* (2009) and Woodgate *et al.* (2015). Another driver and benefit to providing a child's EOL care at home was that the parents felt they had regained control over their child's care.

The parents struggled to emotionally survive and adapt to the outside world again, in the period after the loss of their child. Similar findings were presented by Vega *et al.* (2014). Providing 24-hour care exhausted parents, an often gave rise to physical and mental health problems that persisted for months and sometimes even years after the child died. This finding, especially in absence of bereavement support, is critical and needs to be taken into account, because the loss of a child has a long-term impact on parental physical and mental health (Kreicbergs *et al.* 2007, Hendrickson 2009). During the child's EOL care, parents described practical support for housekeeping as a top priority, since household tasks interfered with care for their dying child. This need persisted even after the child's death. Parents also wanted more home-oriented EOL services, including psychological support (Collins *et al.* 2016). An intact social network with relatives, friends and neighbours proved to be a major supportive resource (Gaab *et al.* 2012).

About half of the children in our sub-study received community care services. This may point to some general problems in palliative care for children suffering from CCCs. Palliative care needs are recognised late in the disease trajectory (Conte *et al.* 2015), and thus EOL care concepts are lacking in these children (Beringer & Heckford 2014), as already reported in North-American countries (Midson & Carter 2010, Keele *et al.* 2013). Like a German study that reported poor access to EOL services in rural areas (Junger *et al.* 2010), our study indicates that families that live farther from the treating hospital tended to receive fewer hours of professional EOL care at home. The distance a family lives from a treating hospital could influence a parent's decision to care for their child at home, and increase the parental burden of care.

Social factors also played an important role in EOL care in the home care setting. As in studies by Feudtner *et al.* (2011a) and Shah *et al.* (2011), our study sample was characterized

by wealthy, well-educated parents who lived in a supportive partnership with a functional supportive social and family network. Even these families needed regulatory changes to accelerate the painfully slow processes of disability and health insurance refunds.

Limitations

The convenience sampling of interview participants led to an over-representation of well-educated parents. Unfortunately, we could not recruit less socially privileged parents, who might have reported different experiences. The requirement of German proficiency excluded participation of immigrants who represent cultural minorities. The generalisability of this sub-study's results to fathers who lost a child might be limited by the low number of fathers in the interviews; however, they were well represented in the PELICAN main study (44%), and expressed their specific experiences and needs.

Conclusion

The use of the system level model enabled us to discover the most important needs of parents, and to identify facilitators and barriers to provision of paediatric EOL care at home. Even though our results are limited to Switzerland, the problem is global: provision of comprehensive paediatric EOL home care remains challenging and demands an extraordinary physical and mental effort from parents. This parental burden of care must be taken into account at all levels when new paediatric EOL home care models are developed, or they will not be sustainable. Legal regulations should ensure access to community care services and to their flexible provision, especially in rural areas (Vollenbroich *et al.* 2015). Financial reimbursement processes must be improved. The model that best meets parental needs is likely to be provision of family-centred EOL care, led by a hospital-based PPC team that

reaches out to the home setting, and includes paid practical housekeeping help and psychological support. Researchers should conduct intervention studies with well-defined outcomes related to caregiving at home, e.g. parental burden during the child's EOL care at home and during the bereavement period.

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